Recent developments in Indigenous health monitoring in Australia

Paper for presentation at the 2009 Meeting of the International Union for the Scientific Study of Population, Morocco

(Session 54: The demography of indigenous populations)

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The authors would like to thank Rhyse Dorward from the Social and Indigenous Group, AIHW, for her assistance in the preparation of this paper.

Abstract

2008 saw a number of important changes in the area of Indigenous heath in Australia. The newly elected Australian Government made a formal apology to the Indigenous people of Australia. The Prime Minister committed his government to "closing the gap between Indigenous Australia and non-Indigenous Australia" in education, employment and health. Closing the life expectancy gap within a generation and halving the gap in the mortality rate for Indigenous children under five within 10 years are the two health-related targets to which all levels of government committed themselves.

This paper provides an examination of the validity of the assumptions that we can accurately measure the gaps as they currently exist, that the ways in which these outcomes are measured are robust, and that data will be available to measure and monitor changes in the outcomes and determinants accurately and meaningfully over time and the extent to which current data are able to measure progress in "closing the gap," using the target of halving the gap in child mortality rates within ten years as an example. The paper begins with a discussion of the broad policy and reporting processes underpinning these targets, then focuses on Indigenous health data, beginning with a historical perspective acknowledging that the ways in which population data are collected and defined are reflective of the historical, political, and social context. The paper then summarizes the four main sources of Indigenous health data and their inherent disadvantages, presents what we are currently able to measure regarding child mortality, and ends with a discussion of the planned data improvements which are critical for ensuring accurate monitoring of the progress being made towards improving the health of Australia's Indigenous people.

Introduction

Population health statistics have been instrumental in documenting the significant health disparities that exist between Indigenous and non-Indigenous people in developed countries, including Australia, Canada, New Zealand, and the United States (AIHW 2009a). As in the other three countries, Indigenous people in Australia have lower life expectancies, higher rates of chronic and preventable illnesses, poorer self-reported health, and higher likelihoods of being hospitalized (Bramley et al 2004; Freemantle et al 2007) than non-Indigenous people. Indigenous Australians also experience significant levels of socioeconomic disadvantage, including lower incomes, lower levels of education, and poorer housing (ABS & AIHW 2005).

The latest Australian data demonstrate the extent of these differences in both determinants and outcomes (AIHW 2008a):

- The gap between Indigenous and non-Indigenous life expectancy at birth in 2005-2007 was 12 years for males (67 vs 79 yrs) and 10 years for females (73 vs 83 yrs)
- Age-specific death rates were higher for Indigenous than non-Indigenous people for all age groups in 2005-2007
- Babies born to Indigenous mothers were twice as likely to be of low birthweight as babies born to non-Indigenous mothers (13% vs 6%), and the infant mortality rate was nearly three times as high for Indigenous babies (12.3/1000 live births vs 4.2/1000 live births)
- Indigenous males and females die from avoidable causes at around 4 to 4.5 times the rate of non-Indigenous males and females
- Indigenous adults self assess their health status as "fair or poor" at twice the non-indigenous rate (33% vs 16%)
- Indigenous Australians have a disability rate of 36%, twice the non-Indigenous rate
- Diabetes prevalence is four times higher in the Indigenous population
- Indigenous Australians are hospitalised at younger ages and at higher rates in every age group
- Hospitalisations for preventable conditions are 7 times higher than the non-indigenous rate
- 46% of Indigenous adults are daily smokers (vs 21% of non-Indigenous adults)
- Indigenous adults are less likely to consume alcohol than other Australians, but of those who drink, a higher proportion drink at long-term risky/high risk levels (34% vs 22%)
- Indigenous Australians have higher rates of sedentary behaviour than non-Indigenous Australians (51% vs 33%)

In February 2008, the newly elected Australian Government issued a formal apology to the Stolen Generations in Parliament, where it publicly committed to "closing the gap" between Indigenous and non-Indigenous Australians in education, employment, and health. The Council of Australian Governments (COAG) identified and endorsed six targets for closing the gap:

- Closing the life expectancy gap within a generation

- Halving the gap in the mortality rate for Indigenous children under five within 10 years
- Ensuring all Indigenous four year olds in remote communities have access to quality early childhood programs within five years
- Halving the gap in reading, writing and numeracy achievements for children within a decade
- Halving the gap for Indigenous students in Year 12 attainment rates or equivalent by 2020
- Halving the gap in employment outcomes within a decade

This was an historic agreement, because for the first time all levels of Australian government committed to a set of specific targets for improving the wellbeing of Indigenous Australians, and agreed to a system of accountability and monitoring through a set of performance indicators. The objectives, outcomes, outputs, performance indicators and performance benchmarks for closing the gap were set out in the National Indigenous Reform Agreement (NIRA). What is also unique about the NIRA is the recognition that a whole of government/whole of community approach is necessary for reducing inequalities, the understanding that these six targets have complex (and interrelated) determinants and thus require multi-pronged approaches, and that high quality data are essential for monitoring progress against the benchmarks. Thus, there was formal recognition that the responsibility for improving the health of Indigenous Australians rests not only with Health Departments, but requires broad improvements in housing, economic status, and educational attainment across the board. NIRA also specifically sets out guidelines and principles for working in partnership with Indigenous communities and organisations to achieve these goals (COAG 2009).

These policies rest on a key set of assumptions related to data quality, however: that we can accurately measure the gaps as they currently exist, that the ways in which these outcomes are measured are robust, and that data will be available to measure and monitor changes in the outcomes and determinants accurately and meaningfully over time.

This paper provides an examination of the validity of these assumptions and the extent to which current data are able to measure progress in "closing the gap," using the COAG target of halving the gap in child mortality rates within ten years as an example. The paper begins with a discussion of the broad policy and reporting processes underpinning these targets, then focuses on Indigenous health data, beginning with a historical perspective acknowledging that the ways in which population data are collected and defined are reflective of the historical, political, and social context. The paper then summarizes the four main sources of Indigenous health data and their inherent disadvantages, presents what we are currently able to measure regarding child mortality, and ends with a discussion of the planned data improvements which are critical for ensuring accurate monitoring of the progress being made towards improving the health of Australia's Indigenous people.

Policy and reporting frameworks

The National Indigenous Reform Agreement encompasses the broad mechanisms, COAG funding agreements, and principles which underpin the six "closing the gap" targets (COAG 2009). It highlights seven COAG-endorsed "Building Blocks" which support the reforms aimed at closing the gaps in health, education, and employment:

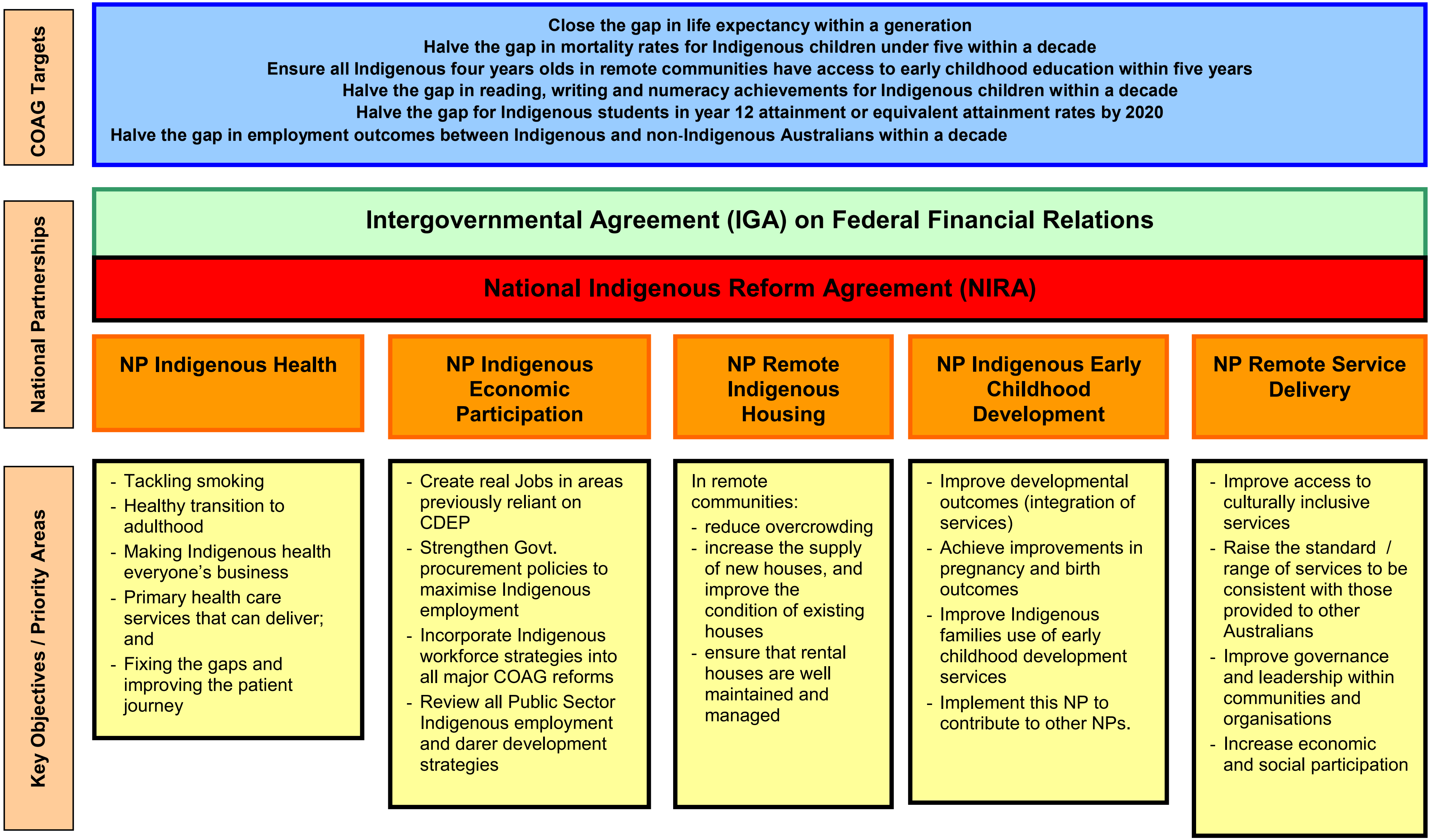
- Early childhood
- Schooling
- Health
- Economic Participation
- Healthy Homes
- Safe Communities
- Governance and Leadership

As noted in the report, these building blocks are interrelated, and improvements in one building block are dependent on improvements in others. These building blocks fit well within a population health perspective which acknowledges that the determinants of health and wellbeing lie in a number of different realms, including individual, service-level, and community and cultural factors.

NIRA also brings together the five key National Partnership Agreements which underpin these building blocks. Figure 1 provides a summary of these Agreements, and their key objectives/priority areas. According to NIRA, "the National Partnerships act on the contributors to health and wellbeing from pre-natal care through birth and early childhood, school and the transition to adulthood. They also address the social determinants of health and wellbeing including education, housing and employment (COAG 2009: A-28)."

For example, the National Partnership on Indigenous Health includes the expansion of primary health care and targeted prevention activities to reduce the burden of chronic diseases, and is expected to lead to:

- Reduced smoking rates among Indigenous people
- Reduced burden of diseases in Indigenous communities
- Increased uptake of Medicare Benefits Schedule funded primary care services to Indigenous people with half of the adult population (15-65 yrs) receiving 2 adult health checks over the next four years
- Improved care coordination
- Reduction in the average length of hospital stay and reduction in readmissions



COAG Targets

Close the gap in life expectancy within a generation
Halve the gap in mortality rates for Indigenous children under five within a decade
Ensure all Indigenous four years olds in remote communities have access to early childhood education within five years
Halve the gap in reading, writing and numeracy achievements for Indigenous children within a decade
Halve the gap for Indigenous students in year 12 attainment or equivalent attainment rates by 2020
Halve the gap in employment outcomes between Indigenous and non-Indigenous Australians within a decade

National Partnerships

Intergovernmental Agreement (IGA) on Federal Financial Relations

National Indigenous Reform Agreement (NIRA)

Key Objectives / Priority Areas

NP Indigenous Health

- Tackling smoking
- Healthy transition to adulthood
- Making Indigenous health everyone's business
- Primary health care services that can deliver; and
- Fixing the gaps and improving the patient journey

NP Indigenous Economic Participation

- Create real Jobs in areas previously reliant on CDEP
- Strengthen Govt. procurement policies to maximise Indigenous employment
- Incorporate Indigenous workforce strategies into all major COAG reforms
- Review all Public Sector Indigenous employment and darer development strategies

NP Remote Indigenous Housing

In remote communities:

- reduce overcrowding
- increase the supply of new houses, and improve the condition of existing houses
- ensure that rental houses are well maintained and managed

NP Indigenous Early Childhood Development

- Improve developmental outcomes (integration of services)
- Achieve improvements in pregnancy and birth outcomes
- Improve Indigenous families use of early childhood development services
- Implement this NP to contribute to other NPs.

NP Remote Service Delivery

- Improve access to culturally inclusive services
- Raise the standard / range of services to be consistent with those provided to other Australians
- Improve governance and leadership within communities and organisations
- Increase economic and social participation

In addition, a National Partnership Agreement on Remote Indigenous Public Internet Access has been signed, and a national strategy for improving the affordability and availability of healthy food for Indigenous people living in remote Australia is being developed for consideration by COAG in November 2009 (COAG 2009).

There are also COAG National Agreements which provide special purpose funding to the States and Territories to improve services for all Australians, including Indigenous Australians. For example, the National Healthcare Agreement is designed to improve health outcomes and the sustainability of Australia's healthcare system, the National Disability Agreement provides a framework and areas of reform for government support to people with disabilities, and the National Affordable Housing Agreement focuses on improving housing availability for all Australians. Thus, the combination of these National Agreements and the National Partnership Agreements provides the funding and the policy support for making improvements in the seven building blocks, which are then expected (over time), to reduce the gaps and meet the six key COAG targets.

NIRA explicitly set out how the COAG Agreements fit together with the building blocks within each of the six targets. Table 1 provides an overview of these relationships for the target of reducing the gap in child mortality by half within 10 years (COAG 2009: p.A38-39).

Table 1: The relationship between COAG agreements, building blocks, and key outputs

Building Blocks	COAG Agreements	Outputs
Early Childhood	Indigenous Early Childhood Development NP	Establishment of a minimum of 35 Children and Family Centres in urban, regional and remote areas with high Indigenous populations and high disadvantage
		Provision of early learning, child care and parent and family support services to Indigenous families at or through each of the Children and Family Centres
		Increased provision of antenatal care services targeted at young Indigenous women
		Increased provision of sexual and reproductive health services for Indigenous teenagers
		Increased provision of maternal and child health services for Indigenous children and their mothers
Schooling	Indigenous Early Childhood Development NP	Establishment of a minimum of 35 Children and Family Centres in urban, regional and remote areas with high Indigenous populations
		Provision of early learning, child care and parent and family support services to Indigenous families at or through each of the Children and Family Centres
	Preventive Health NP	Meals programs in early childhood education programs
Health	Indigenous Early Childhood Development NP	Increased provision of antenatal care services targeted at young Indigenous women
		Increased provision of sexual and reproductive health services for Indigenous teenagers
		Increased provision of maternal and child health services for Indigenous children and their mothers
	Closing the Gap in Indigenous Health Outcomes NP	Reduction in alcohol use and smoking
		More flexible models of service delivery and improved coordination of care
	Preventive Health NP	Reduction in alcohol use and smoking
		Promotion of breastfeeding
Economic Participation	National Healthcare Agreement	Increase number and quality of training of Indigenous health workforce
	Closing the Gap in Indigenous Health Outcomes NP	Increase number and quality of training of Indigenous health workforce
Healthy Homes	Remote Indigenous Housing NP	Improve environmental housing (sewerage and water quality) to combat communicable disease
	Indigenous Early Childhood Development NP	Establishment of a minimum of 35 Children and Family Centres in urban, regional and remote areas with high Indigenous populations and high disadvantage
		Provision of early learning, child care and parent and family support services to Indigenous families at or through each of the Children and Family Centres
Safe Communities	Closing the Gap in Indigenous Health Outcomes NP	Addressing alcohol/substance abuse and harm through prevention, diversion and treatment services

As part of these funding agreements, the Commonwealth and States/Territories agreed to a system of monitoring progress towards meeting these targets through a set of Indigenous-specific performance indicators. Tables 2 and 3 provide a summary of these indicators for the two health-related outcomes, life expectancy and child mortality (COAG 2009).

Table 2: Life Expectancy Performance Indicators

Performance Indicator	Level of Reporting	Baseline
Estimated life expectancy at birth	National, by jurisdiction, male & female	2005-2007
Mortality rate (and excess deaths by leading causes)	National, by jurisdiction, male & female	2007
Hospitalisation rates by principal diagnosis	National, by jurisdiction	2007-2008
Rates of current daily smokers	National, by jurisdiction	2004-2005
Average daily alcohol consumption & associated risk levels	National, by jurisdiction	2004-2005
Levels of obesity, BMI	National, by jurisdiction	2004-2005
Levels of physical activity	National, by jurisdiction	2004-2005
Access to health care compared to need:[1] – Percentage who accessed health care by type of service – Level of need for a health care service by type of service	National, by jurisdiction	Varies by source

Table 3: Child Mortality Performance Indicators

Performance Indicator	Level of Reporting	Baseline
Under 5 child mortality rate (and excess deaths)	National, by jurisdiction	2007
Mortality rates (and excess deaths by leading causes): perinatal, infant, 1-4 yr, 0-4 yrs	National, by jurisdiction	2006-2007
Child (under 5) hospitalisation rates by principal diagnosis	National, by jurisdiction	2007-2008
Proportion of babies low birthweight	National, by jurisdiction	2006
Tobacco smoking during pregnancy	National, by jurisdiction	2006
Antenatal care: – Proportion of mothers attending prenatal care in 1st trimester – Proportion of mothers attending 5 or more antenatal session	National, by jurisdiction	2006

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[1] Calculating these measures is quite complex in practice and requires data from a number of different sources on a number of outcomes. For example, data is required on health status, health services accessed & barriers to access (National Aboriginal and Torres Strait Islander Health Survey); access to types of health services and health professionals (Community Housing and Infrastructure Needs Survey); expenditure per person by health goods & services type (AIHW Health Expenditure data); Number of GPs per 1000 population (Medicare); Workforce engage in health related occupations (AIHW Labour Force Surveys); Hospital separations (AIHW National Hospital Morbidity Database).

A newly established body—the COAG Reform Council (CRC) will report annually on all indicators under each of the national agreements. Monitoring these indicators will help to assess the progress made by each state/territory's towards achieving the agreed outcomes in each agreement including progress towards the Closing the Gap targets as part of the National Indigenous Reform Agreement.[2] Some modelling work on trajectories between the baseline rate and the rate needed to meet the target within the agreed-upon time frame will be required to assess progress towards the six targets annually.[3] These trajectories will be recalculated if the gap widens because of changes in the non-Indigenous rates.[4]

A number of the indicators in the National indigenous reform Agreement are already being routinely reported in the Aboriginal and Torres Strait Islander National Health Performance Framework (HPF), the overarching structure for reporting on the health (and health determinants) of Indigenous Australians and in the Overcoming Indigenous Disadvantage: Key Indicators report (SCRCGSP 2009). The HPF was originally developed by the Standing Committee on Aboriginal and Torres Strait Islander Health (SCATSIH 2006) through a series of consultations which resulted in the three-tiered Framework shown below in Figure 2.[5] The framework and the set of 70 indicators have been endorsed by Health Ministers.

Tier 1—health status and health outcomes: This Tier includes the prevalence of health conditions (e.g. circulatory disease, diabetes), human function (e.g. disability), life expectancy and well-being and deaths, to provide an overall indication of current health status and recent trends in the health status of Aboriginal and Torres Strait Islander peoples on a range of health issues. These issues include child and maternal health, chronic diseases, injury, communicable diseases, social and emotional wellbeing and overall health status.

Tier 2—determinants of health: This Tier focuses on factors outside the health system that impact on the health of Aboriginal and Torres Strait Islander peoples. These factors include socioeconomic status (e.g. income and education), environmental factors (e.g. overcrowding), community capacity (e.g. child protection), health behaviours (e.g. risky alcohol consumption and dietary behaviours) and person-related factors (e.g. prevalence of overweight and obesity) which have been shown to have a strong association with both disease and ill-health.

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[2] Public reporting on the progress being made (or the lack thereof) will also come from the Productivity Commission's *Overcoming Indigenous Disadvantage: Key Indicators* reports (SCRGSP 2009). These reports were originally commissioned by COAG in 2002, and were produced in 2003, 2005, 2007, and 2009. Changes were made to the original reporting framework to align the data reporting with the COAG and NIRA policy goals and priorities. Most of the health-related data included in these reports comes from AIHW (Australian Institute of Health and Welfare) and ABS (Australian Bureau of Statistics) publications and analyses.

[3] At the national level and the jurisdictional level. However, the Agreement notes that data improvements are required before the indicators can be measured accurately at a jurisdictional level.

[4] The Closing the Gap policy, by definition, requires a comparison between Indigenous and non-Indigenous outcomes. There are two options for measuring the gap – the absolute difference (rate difference) and the relative difference (rate ratio). The rate difference is the Indigenous rate minus the non-Indigenous rate, while the rate ratio is the Indigenous rate divided by the non-Indigenous rate. For trend analyses in particular, the rate ratio alone can sometimes be misleading. In cases where the non-Indigenous rate is particularly small and the Indigenous rate is particularly high, the situation can arise where there is an improvement in both the Indigenous and non-Indigenous rates with the rates diverging but the ratio decreasing (or vice versa). In such cases, the rate difference is a more accurate reflection of the pattern in trends.

[5] Based on the National Health Performance Framework (NHPC 2001).

Figure 2: Aboriginal and Torres Strait Islander Health Performance Framework Measures

Health Status and Outcomes (Tier 1)

Health Conditions
1.01 Low birthweight infants
1.02 Top reasons for hospitalisation
1.03 Hospitalisation for injury and poisoning
1.04 Hospitalisation for pneumonia
1.05 Circulatory disease
1.06 Acute rheumatic fever & rheumatic heart disease
1.07 High blood pressure
1.08 Diabetes
1.09 End stage renal disease
1.10 Decayed, missing, filled teeth
1.11 HIV/AIDS, hepatitis C and sexually transmissible infections
1.12 Children’s hearing loss

Human Function
1.13 Disability
1.14 Community functioning

Life Expectancy & Wellbeing
1.15 Perceived health status
1.16 Social and emotional wellbeing
1.17 Life expectancy at birth
1.18 Median age at death

Deaths
1.19 Infant mortality rate
1.20 Perinatal mortality
1.21 Sudden infant death syndrome
1.22 All causes age standardised deaths rates
1.23 Leading causes of mortality
1.24 Maternal mortality
1.25 Avoidable and preventable deaths

Determinants of Health (Tier 2)

Environmental Factors
2.01 Access to functional housing with Utilities
2.02 Overcrowding in housing
2.03 Environmental tobacco smoke

Socioeconomic Factors
2.04 Educational participation and attainment of Aboriginal and Torres Strait Islander adults
2.05 Years 10 and 12 retention and attainment
2.06 Year 3, 5 and 7 literacy and numeracy
2.07 Employment status including CDEP participation
2.08 Income
2.09 Housing tenure type
2.10 Index of disparity

Community Capacity
Demography
2.11 Dependency ratio
2.12 Single-parent families by age group

Safety and Crime
2.13 Community safety
2.14 Contact with the criminal justice system
2.15 Child protection

Other
2.16 Transport
2.17 Indigenous people with access to their traditional lands

Health Behaviours
Tobacco, alcohol and other drug use
2.18 Tobacco use
2.19 Tobacco smoking during pregnancy
2.20 Risky and high risk alcohol consumption
2.21 Drug and other substance use including inhalants
Physical activity
2.22 Level of physical activity
Nutrition
2.23 Dietary behaviours
2.24 Breastfeeding practices
Other health behaviours
2.25 Unsafe sexual practices

Person-related Factors
2.24 Prevalence of overweight and obesity

Health System Performance (Tier 3)

Effective/Appropriate/Efficient
3.01 Antenatal care
3.02 Immunisation (child and adult)
3.03 Early detection and early treatment (including cancer screening)
3.04 Chronic disease management
3.05 Differential access to key hospital procedures
3.06 Ambulatory care sensitive hospital admissions
3.07 Health promotion

Responsive
3.08 Discharge against medical advice
3.09 Access to mental health services
3.10 Aboriginal and Torres Strait Islander Australians in the health workforce
3.11 Competent governance

Accessible
3.12 Access to services by types of service compared to need
3.13 Access to prescription medicines
3.14 Access to after hours primary health care

Continuous
3.15 Regular GP or health service
3.16 Care planning for client with chronic diseases

Capable
3.17 Accreditation
3.18 Aboriginal and Torres Strait Islander people in Tertiary Education for health related disciplines

Sustainable
3.19 Expenditure on Aboriginal and Torres Strait Islander health compared to need
3.20 Recruitment and retention of clinical and management staff (including GPs)

Notes: The **Safe** domain is measured within the National Health Performance Committee framework.

Tier 3—health system performance: This Tier includes measures of the performance of the health system including population health, primary health care and secondary/tertiary care services. Six domains are covered: effectiveness of health services, responsiveness of health services to Aboriginal and Torres Strait Islander communities and individuals, accessibility of services, capability and sustainability. This Tier includes measures that deal with a range of programs and service types including child and maternal health, early detection and chronic disease management, continuous care, assess to secondary/tertiary care, the health workforce and expenditure.

The most recent report against these criteria (AIHW 2008a) included detailed information on 70 measures using administrative data, vital statistics, Indigenous-specific and general surveys, and underlying population estimates from the census.

The advantage of the ATSIHPF is that it gives a well-conceived structure to the information on Indigenous health that is available and highlights gaps in knowledge. The framework also acknowledges the interactions between service delivery, individual and contextual determinants of health, and health outcomes. However, as described in the next section, the serious methodological problems with the source data on Indigenous health in Australia mean that interpretation of the findings must be undertaken with care, and will make monitoring progress towards the Closing the Gap targets difficult.

Indigenous health data collection and governance

Historically, the collection of reliable and valid data related to Indigenous Australians was haphazard at best, and marred by inconsistencies in the definition of Aboriginality and coverage. How Aboriginality has been defined (and by whom), and the types of data collected are socially, politically, and culturally defined.

Until 1967, Aboriginal people were not recognised in the Australian Constitution and they were excluded from official statistics. In 1967, following years of campaigning, a referendum was held in which 90.77% of (non-Indigenous) Australians supported alterations to Australia's Constitution allowing Aboriginal and Torres Strait Islanders to be counted in the census and giving the Commonwealth Government the power to make specific laws for Indigenous people.[6]

The outcome of the referendum led to the practical question about how to define Aboriginality for the purpose of the census and for eligibility for specific programs. Prior to the referendum, definitions of Aboriginality were based on "blood," and an Aboriginal person was defined as one with more than 50% Aboriginal blood. Throughout the 1970s, most Commonwealth legislation defined an Aboriginal as a "person who is a member of the Aboriginal race of Australia,".

In the 1980s a new definition was proposed: An Aboriginal or Torres Strait Islander is a person of Aboriginal or Torres Strait Islander descent who identifies as an Aboriginal or Torres Strait Islander and is accepted as such by the community in which he (she) lives. Thus, there are three parts to this definition – descent, self-identification, and community recognition. The Federal Government adopted this definition for determining eligibility for services, as did many State/Territory policies and laws (Gardiner-Garden 2000).

The broadening of the definition to include social elements meant that many more people fell within the official definition. From a practical perspective, however, it is difficult to

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[6] The Referendum did not give Indigenous people the right to vote or grant Indigenous people citizenship rights.

assign identity based on all three components of the definition.[7] Therefore, eligibility for Indigenous-specific health services and collection of population-related data are based on questions that relate to descent and self-identification only (AIHW & ABS 2006).[8] Unfortunately, different wordings of this question and different coding procedures were used in different data collection systems and processes, making comparison across time and data sets difficult.

Best Practice Guidelines are in the process of being implemented by jurisdictions to improve the collection of information on Aboriginal or Torres Strait Islander people in key national health data sets, by setting out best practices that can be implemented by data collectors, data managers and data custodians (AIHW 2009). The focus is on ensuring that the same question is asked (in the same way) in all data sets: *"Are you [is the person] of Aboriginal or Torres Strait Islander origin,?"* with the response categories of *"No," "Yes, Aboriginal," "Yes, Torres Strait Islander"* and respondents asked to tick all that apply so that a both Aboriginal and Torres Strait Islander category can be created. [9]

While having the same question included in all data collection sets would certainly improve data quality, it is important to acknowledge that Indigenous identification is subject to social and cultural changes over time and is influenced by the attitudes of the majority group towards the minority group, along with Indigenous people's attitudes and feelings about themselves. Identification as Indigenous in Australia is influenced by the way in which Indigenous people have been treated in the past, the way in which "Indigenous issues" are presented by the larger community, and the number of mixed marriages (Ross 1999). [10] For example, between the 1991 and 1996 census, the Indigenous population increased by 33%, of which 19% was thought to be change in identification and 14% was demographic. Changes in Indigenous identification were greatest where the population has high numbers of people of mixed parentage, e.g. south-east Australia.

The other major issue with the collection of data on Indigenous status is that even if a question on identity does appear on a form (eg. hospital admission, death registration), research has shown that some registry staff, health workers and professionals often forget to ask the question, guess about Indigenous status based on appearance, are reluctant to ask what may appear to be a discriminatory question about race, or believe race is irrelevant to the service being provided.

Indigenous people themselves may also be concerned about being discriminated against if they identify. Although the policy of the forced removal of Indigenous children is no longer in place, the impact of this policy is still being felt within Indigenous communities and families, and people are often suspicious of why a person "in authority" would want to know if they are an Aboriginal or Torres Strait Islander. From a health system perspective, however, it is critical that Indigenous people identify as such in order to qualify for a number of Medicare-funded services specifically targeted towards the Indigenous population. For example, there are Medicare Benefits Funded health assessments for all

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[7] There are also those who oppose the implication that a person is not Indigenous unless recognised by other people.

[8] Eligibility for other services, such as Indigenous-specific scholarships and housing allocation still relies on all three aspects of the definition.

[9] Grouping people as Indigenous/non-Indigenous also assumes homogeneity within the group, or that Indigenous status is a meaningful sociological category. There is certainly a great deal of variation within the Indigenous community, but it is important to accurately measure the inequities between the status of Indigenous Australians and non-Indigenous Australians at the population level. Further, more in-depth research can then analyse the differences in wellbeing *within* the Indigenous community.

[10] In 2001, 50% of Indigenous households were mixed.

ages, access to specific Pharmaceutical Benefits Scheme listings, and Indigenous-specific child and adult immunisation schedules. Identification would also ideally lead to appropriate and culturally safe care, including referrals to Aboriginal and Torres Strait Islander-specific services if patients desire.

Since 1997, efforts to collect high quality data related to the health and welfare of Australia's approximately 517,000 Aboriginal and Torres Strait Islanders[11] have been governed by the Aboriginal and Torres Strait Islander Health Information Plan (AIHW 1997),[12] with the first of the ABS & AIHW two-yearly reports on *The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples* published that same year.

In 2000, the National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data (NAGATSIHID) was established to improve the quality and availability of data, strategically coordinate these processes, and ensure that the data collected appropriately reflect and meet the needs of Indigenous Australians, while AIHW and the ABS hold primary responsibility for the national collation and analysis of the data (AIHW & ABS 2006).

NAGATSIHID has a majority of Aboriginal and Torres Strait Islander members, and is chaired by a member of the Australian Health Ministers Advisory Council. Its membership includes three Indigenous advisors on Aboriginal and Torres Strait Islander health and welfare, an epidemiologist with expertise in Indigenous health issues, as well as representatives of the National Aboriginal Community Controlled Health Organisation, the National Aboriginal and Torres Strait Islander Health Officials Network, the AIHW, the ABS, the Australian Government Department of Health and Ageing, the Australian Government Office for Indigenous Policy Coordination, the Australian Institute of Aboriginal and Torres Strait Islander Studies, the Torres Strait Regional Authority and the National Health Information Standards and Statistics Committee.

NAGATSIHID is responsible for

- continuing the implementation of the 1997 *Aboriginal and Torres Strait Islander Health Information Plan – this time let's make it happen* (AIHW 1997). This includes monitoring and improving Indigenous identification in a range of data collections including censuses, birth registration, death registration, hospital separations, cancer registers, community mental health services, alcohol and other drug treatment services and other data collections
- advising the Australian Institute of Health and Welfare (AIHW) and the Australian Bureau of Statistics (ABS) on information and data priorities
- providing advice to the Australian Government's Department of Health and Ageing on the Aboriginal and Torres Strait Islander Health Performance Framework (HPF) (AIHW & ABS 2006).

Sources of Indigenous health data

There are four main sources of data on Indigenous health in Australia, each with its own strengths and drawbacks:

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[11] Representing 2.5% of Australia's 21 million people.

[12] A National Health Information Agreement governing the collection of all population health data was first signed in 1993.

- Five-yearly Australian Census of Population and Housing
- Administrative data collections: registries (births, deaths and marriages), hospitals, clinics, health centres, GPs.
- National sample surveys which include Indigenous respondents
- Surveys of Indigenous people only: e.g National Aboriginal and Torres Strait Islander Health Survey (NATSIHS), National Aboriginal and Torres Strait Islander Social Survey (NATSIS)

Census data

Problems associated with the five-yearly Census of Population and Housing includes under-enumeration of the Indigenous population and the high level of non-response rate to the Indigenous status question. In 2006, 1.13 million census records did not have Indigenous status recorded, two and a half times the number of individuals counted as Indigenous (ABS 2007a). In addition, changes in the propensity of individuals to identify as Indigenous have been an issue.

The ABS conducts a Post Enumeration Survey (PES) beginning about 3 weeks after the census to determine how many people were missed in the census and how many were counted more than once. The amount of the undercount is then used to calculate population estimates for the states/territories and Australia as a whole. For 2006, the survey had a sample size of approximately 40,000 households across Australia (ABS 2007a). The 2006 PES also included remote areas and discrete Indigenous communities for the first time. Previous PESs have excluded these areas because of the additional costs and the need to use the same local contacts as Census, which was considered likely to compromise the independence of the PES. Including these communities ensures that the geographic scope of the 2006 PES is more complete than it has been in the past (ABS 2007b) .

The ABS produces three sets of population estimates for the Indigenous population:

- Census counts (Census years only)
- Estimated Resident Population (Census years only)
- Experimental Estimates and Projections (inter-census years).

The Estimated Resident Population (ERP) is the official measure of the Indigenous population of Australia. To arrive at the ERP, the Census count is adjusted for net under-count, and unknown Indigenous status.[13] The Indigenous net undercount in the 2006 Census was estimated to be 59,200 persons (ABS 2008). ERPs are available by 5 yr age group, sex, state/territory and geographic location.

Experimental estimates and projections are estimated for inter-census years and are available by 5 year age group, sex and state/territory. Following each Census, a series of Indigenous projections and backcasting estimates are produced. It takes approximately three years after the census is completed for these estimates to be released. Current Indigenous population series based on the 2001 Census are available from 1991 to 2009. Projections and backcasts based on the 2006 Census will be available later in 2009 based and will provide

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[13] More information on how the ERP is calculated is available in the ABS publication *Population Distribution, Aboriginal and Torres Strait Islander Australians* (cat. no. 4705.0) and the Indigenous estimated resident population - method of calculation feature article in *Australian Demographic Statistics*, March quarter 2007 (cat. no. 3101.0).

data from 1991 to 2021. These data will replace the previous estimates and projections, which will lead to the readjustment of rates that were previously calculated with the older data.

The ERP is recommended for calculating population rates in Census years or within two years of a Census collection. Experimental Estimates and Projections are recommended to be used for the calculation of population rates for time series, for grouped years of data and for data that is not close to a Census year. Census counts are never used for the calculation of rates as these do not adjust for Indigenous under-count, or unknown Indigenous status in the Census.

Administrative and vital statistics data

The major issue in using administrative and vital statistics data is the variability in the quality of reporting on Indigenous status. Under-identification is a significant problem in hospitalization data, death registrations, birth registrations, immunization registries, cancer registries, and communicable disease data, rendering data from some of the states/territories unusable (AIHW 2008a). The degree of under-identification varies by State and Territory and by remoteness, changes with time, and changes at different rates in different jurisdictions. When the identification question is not asked, the outcome is that there are large numbers of “not stated” responses, which, until recently, were included in the “non-Indigenous” category.

The collection of vital statistics data serves as an example of the complexity of collecting robust Indigenous health data. For example, when someone dies, funeral directors fill in death notification forms and are required to send them to the Registrars of Births, Deaths and Marriages in their own jurisdiction within 7 days of burial/cremation in most states/territories, or within 14 days of the death in others. The death notification form includes a question on Indigenous status. The funeral director fills in this information by asking the family, from personal knowledge, or by observation of the body. Because of this process, there can be significant under-reporting or mis-reporting of Indigenous status. States and territories then provide their death registration data to the Australian Bureau of Statistics (ABS) on a monthly basis.

Thus, when an Indigenous person dies, the death will be classified as an Indigenous death **only** if all the following events take place (Cunningham and Paradies 2000):

- The question about Indigenous status is asked
- The question is answered correctly by a relative or friend
- The answer is recorded correctly on the form
- The form is completed and is submitted to the registry
- The form is processed and the Indigenous status is correctly entered into the system
- The information is retained through editing and data processing stages and is transmitted correctly from the jurisdictional registries to the ABS

Cause of death information is collected on a different form from the attending doctor, who must complete and sign the medical certificate of the cause of death within 48 hours of the death. This certificate includes a question on Indigenous status. When completed, the certificate is then sent to the Registrar of Births, Deaths and Marriages. If a death is referred to the coroner, there may be a delay in establishing the cause of death. The ABS then uses this information to code causes of death.

Until recently, only the death notifications from the funeral directors were used as the basis for recording Indigenous status. Since 2007, however, the ABS has used information from both the medical certificate and the death registration form to code Indigenous status.

In order to estimate the extent to which Indigenous status was underreported in deaths data, the ABS undertook the Census Data Enhancement Indigenous Mortality Quality Study, which linked 2006 Census records with death registrations from 9 August 2006 to 30 June 2007. The results showed a coverage rate of 85% nationally. This estimate is considerably higher than estimates for earlier periods which indicated that coverage was only about 55% nationally (ABS 2008b).

Information on birth comes from two separate sources and is processed by two different agencies. Parents are required to register births with their state/territory registries within 60 days of a birth.[14] The form collects information on the Indigenous status of both parents, but does not ask about the Indigenous status of the baby. These data are sent to the ABS on a monthly basis for collation and analysis. Analysis of the quality of this data has shown variation in the estimated identification of Indigenous births across states, and because the data are reliant on parental registration, it also underestimates the total number of births. The ABS estimates the coverage of Indigenous birth registrations for the period 2002–06 to be 95%. However, almost one-quarter of Indigenous births actually occurred in the year prior to the year of registration or in an earlier year (ABS 2006).

The second set of birth information data comes from the National Perinatal Data Collection (NPDC) from the AIHW National Perinatal Statistics Unit. Midwives and other staff, using information obtained from mothers and from hospital and other records, complete notification forms for all births of at least 400 grams birthweight or at least 20 weeks gestation. The collection records the Indigenous status of the mother only. Data are held in state/territory perinatal databases and are provided to the National Perinatal Statistics Unit yearly.

Because the NPDC collects behavioural, medical, and service-use details throughout a woman's pregnancy, as well as data on birth outcomes for the baby, the data can be used to analyse the determinants of birth outcomes and how they differ by Indigenous status. Currently, however, while there is significant inter-state/territory variation in the variables that are collected and how they are defined, the data collection has the advantage of both numerator and denominator being from the one data source when calculating rates, thus avoiding the problem inherent to calculating many of the rates where the numerator and denominator are derived from two separate collections—each with its own set of data issues— resulting in a numerator/denominator mismatch (e.g. death rates).

As the NPDC is a midwives data collection, it focuses on mothers and babies only. Therefore, only outcomes of babies born to Indigenous mothers are currently reported. The NPDC can't be used to report on approximately 30% of babies born to Indigenous fathers and non-Indigenous mothers as these babies are not identified as Indigenous in that collection. This issue is currently being considered as part of the COAG reforms to improve

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[14] In some states/territories, health professionals are also required to notify the Registrar.

monitoring of outcomes for Indigenous Australians by providing resources to "Close the Data Gap".

Survey data

Because of the small size of the Indigenous population (517,200), limited capture of Indigenous Australians is an issue in general surveys which gather important health and behavioural data about the population as a whole, and provide an opportunity for comparing Indigenous and non-Indigenous Australians (eg. the National Health Survey, and the National Drug Strategy Household Survey). In some instances, there are also methodological questions related to whether survey questions targeted at the mainstream Australian population are reliable and valid for the Indigenous population.

Two national Indigenous-specific surveys are conducted periodically. The first National Aboriginal and Torres Strait Islander Social Survey was conducted in 1994 (17,000), the second in 2002 (9400), the third in 2008,[15] and future surveys will be conducted at six yearly intervals. The first National Aboriginal and Torres Strait Islander Health Survey was conducted in 2004-2005 (10,439), and the next survey will be in 2010-2011 and 6 yearly thereafter. While the Indigenous-specific surveys provide information on key health outcomes and determinants, their numbers are too small to permit disaggregation below the level of the jurisdiction.

Implications

The problems inherent in data related to Indigenous Australians have serious implications for the ability to accurately measure health determinants, outcomes, and changes over time. To assess changes in health outcomes, we need rates, which depend upon reliable data for both numerators and denominators. If either of these figures is unreliable then caution must be exercised when using rates to compare the health of Indigenous Australians to non-Indigenous Australians until better data is available or appropriate statistical techniques can be used to adjust the data for the level of under identification. For example, recent audits of hospital data undertaken by the AIHW in the different jurisdictions showed that the completeness of identification nationally to be around 89% —with identification being more complete in remote area relative to urban areas. National hospital data is currently being adjusted for under identification before the data is being reported. Similarly, work is currently being undertaken to assess the level of under identification in mortality data using data linkage.

The following section uses the COAG target of halving the gap in child mortality to highlight these data issues from a practical, policy perspective. It compares the data that are currently available with the measures that are needed to evaluate changes in outcomes.

Closing the gap in child mortality

The risks of infant and child mortality are not randomly distributed throughout society, but are reflective of significant social and economic disparities. From a policy perspective, it is important that we examine the determinants of change in outcomes, not simply the outcomes themselves. The determinants and explanations for the inequalities in Indigenous

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[15] Final sample size has not yet been made available.

health (both adult and child) are complex, deep-rooted, and include historical factors such as the impact of colonisation as well as socioeconomic disadvantage (Zubrick et al 2005; aradies 2007; McDermott et al 1998). These are difficult factors to disentangle theoretically, much less empirically. However, they are also important to understand if effective and meaningful policies are to be developed.

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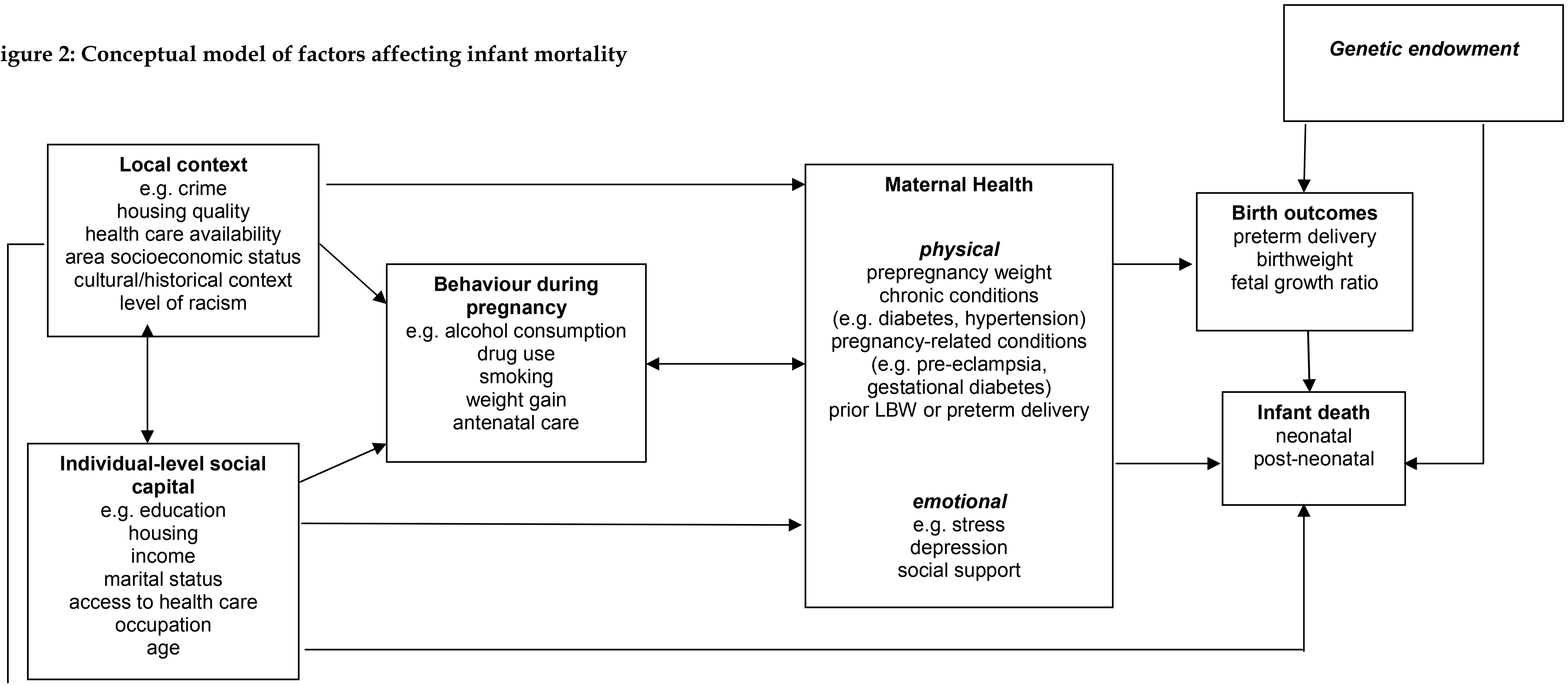
Figure 2 presents a generic conceptual framework outlining the theoretical linkages between a series of individual and contextual factors and infant/fetal health.

Figure 2: Conceptual model of factors affecting infant mortality



Maternal health status (both physical and emotional) and the fetus' genetic endowment are the only domains with direct, biological links to the birth outcomes of preterm delivery, birthweight, and fetal growth. Local context, individual-level social capital, and behaviour during pregnancy work through maternal health to influence birth outcomes. These domains are not independent, but interrelated. While the conceptual model focuses on infant mortality, it could easily be extended to include the factors that affect the risk of dying during early childhood.

While only maternal health and genetic endowment directly affect birth outcomes, other domains may directly affect infant mortality. Birth outcomes are the largest predictors of survival in the neonatal period, but exogenous environmental and maternal/family behaviours play a more prominent role in postneonatal mortality (eg. through SIDS or injuries). Available resources, both individual and contextual, may also affect access to timely medical care for illnesses or for well-baby care (including immunizations). Due to space constraints, the framework is not able to include specific post-birth maternal behaviours or risk factors.

This figure is useful because it highlights the types of variables necessary to understand differences in infant mortality between populations. For example, how do maternal health factors differ between pregnant Indigenous women and pregnant non-Indigenous women? How do behaviours differ, and how does that relate to the local context as well as the women's individual characteristics? Evidence has shown that smoking during pregnancy is one of the largest modifiable risk factors for miscarriage, stillbirth, premature birth, low birthweight and fetal growth retardation (Wills and Coory 2008). In 2006, 52.2% of Indigenous mothers and 15.6% of non-Indigenous mothers reported smoking during pregnancy.16 Babies born to Indigenous mothers were twice as likely to be of low birthweight as babies born to non-Indigenous mothers (13% vs 6%). Ideally we would like to know how both of these factors (smoking and low birthweight) are related to the other domains in the model, and whether these relationships are the same for Indigenous and non-Indigenous women.

As previously presented in Table 3, several of NIRA's key performance indicators fall within this framework, including maternal behaviours (tobacco smoking during pregnancy and antenatal care use), birth outcomes (proportion of babies born low birthweight), and the outcome measures of perinatal[17] and infant mortality.[18] Child hospitalisation rates and child mortality[19] rates are the other key performance indicators.

Calculating the perinatal, infant, and child mortality rates requires data on the number of births, fetal deaths, infant/child deaths, causes of death, and population data on the number of children aged 0-4. As noted in the previous section, there are data quality issues with the numerators and denominators with all of these measures. Table 4 provides an overview of the states and territories with acceptable data for each of the mortality rates and cause of death data, along with the most recent period for which the data are available. The definition of acceptable data relies

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[16] Data for NSW, WA, SA, the ACT, and NT only. Queensland only began collecting smoking status on 1 July 2005.

[17] deaths of infants within 28 days of birth (neonatal death) + deaths of fetuses that weigh at least 400 grams or are of at least 20 weeks gestation/1000 live births

[18] number of deaths of babies between birth and one year of age/1000 live births

[19] can be calculated as either deaths among 0-4 year olds/100,000 population or is sometimes calculated as deaths of children 1-4/100,000 population to separate it from infant mortality

on judgment about each data set thorugh audit work, linkage work or stability of estimates overt time. While data may be acceptable for reporting in a number of jurisdictions, these data should not be compared across jurisdictions without prior adjustments for the level of under identification.

Table 4: States/Territories with Acceptable Data, Child Mortality Performance Indicators[20]

Mortality Rate	**States/Territories with Acceptable Data**	**Most Recent Period reported**
Child (0-4 yrs) mortality rate Cause of death (0-4 yrs)	NSW/Qld (combined) & WA/SA/NT (combined) Qld, WA, SA, NT (combined)	2005-2007 2002-2006
Perinatal mortality rate Perinatal cause of death	NSW, Qld, WA, SA, NT Qld, WA, SA, NT (combined)	2003-2005 2001-2005
Infant mortality rate Infant cause of death	NSW, Qld, WA, SA, NT Qld, WA, SA, NT (combined)	2005-2007 2002-2006
Child (1-4 yrs) mortality rate Cause of death (1-4 yrs)	NSW/Qld (combined) & WA/SA/NT (combined) Data not published	2005-2007
Child (0-4) hospitalisation rates by principal diagnosis	NSW, Vic, Qld, WA, SA, NT	2004-2005
Proportion of babies born low birthweight (<2500 grams)	All except Tasmania	2003-2005
Tobacco smoking during pregnancy	NSW, Qld, WA, SA, Tas, ACT, NT[21]	2005
Antenatal care:		
– Proportion attending prenatal care in 1st trimester	NSW, NT	2005
– Proportion attending 5 or more prenatal sessions	Qld, SA, NT	2005

Table 4 demonstrates the inherent problems with accurately measuring the gaps in child mortality outcomes and the determinants of those outcomes. At this point, the gaps in perinatal and infant mortality can be measured at the state/territory level *only* for NSW, Queensland, Western Australia, South Australia and the Northern Territory. Because child deaths are a relatively rare event, data even for the states/territories with relatively reliable Indigenous status reporting had to be combined to calculate child mortality rates that could be considered stable. Looking at cause of death data is quite important from a theoretical and policy perspective but to do so data are combined over a number of years and for a number of jurisdictions. Data for determinants (hospitalisations, low birthweight, smoking, and antenatal care use) are also not available for every jurisdiction.

The table also shows that there will be a time lag in data availability relative to policy change. While the policy changes began in 2008, it will take time for data to be collected and released. However, data supply is expected to speed up considerably to support the annual reporting for indicators in the various National Agreements by the COAG Reform Council.

Also, it is important to ensure that any changes in the gap properly apportion the change to the extent of changes in non-Indigenous rates and Indigenous rates. For

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[20] AIHW 2008a.

[21] Smoking-related questions differ across the states/territories

example, if infant mortality rates in the non-Indigenous population worsen, the gap will narrow by definition even with no improvement in Indigenous infant mortality..

Because the level of under-identification in the data is unknown and is variable by jurisdiction, it is difficult to know to what extent Indigenous/non-Indigenous differences in these rates reflect true differences in underlying health status or is an artefact of the data quality issues. This issue will be discussed in more detail in the discussions of perinatal mortality in table 6.

Table 5 presents the most recent estimates for the overall child mortality rate, and the difference between the rates for Indigenous and non-Indigenous children. These data show that in each of the two combined areas, Indigenous children are significantly more likely to die before they turn five than are non-Indigenous children. The gap in 2005-2007 was 110 child deaths in NSW and Queensland per 100,000 population, while the gap in Western Australia, South Australia, and the Northern Territory combined was 236 child deaths per 100,000 population.[22]

Table 5: Child mortality rates (deaths children 0-4/100,000 population), 2005-2007[23]

States/Territories	Indigenous	Non-Indigenous	Difference
NSW/Qld	218.9	109.4	109.5
WA/SA/NT	326.7	91.1	235.6

Table 6 shows the most recent estimates of the perinatal mortality rates for Indigenous and non-Indigenous infants by state/territory, while Table 7 shows the most recent estimates for infant mortality by state/territory.

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[22] The higher rates in WA/SA/NT may reflect better reporting of Indigenous status in death data in these states.

[23] Source: Overcoming Indigenous Disadvantage Key Indicators 2009 report, web-based detailed appendix tables, based on ABS data calculations. Data tables at www.pc.gov.au/gsp/reports/indigenous/keyindicators2009. Victoria, Tasmania and the ACT are excluded due to small numbers of Indigenous deaths. Deaths for whom Indigenous origin was not stated were not been prorated between Indigenous and non–Indigenous deaths. As a result, Indigenous and non-Indigenous mortality rates may be underestimated. Denominators used in the calculation of rates for the Indigenous population are Experimental Estimates and Projections, Aboriginal and Torres Strait Islander Australians (ABS cat. no. 3238.0, low series, 2001 base). There are no comparable population data for the non-Indigenous population. Denominators used in the calculation of rates for comparison with the Indigenous population have been derived by subtracting Indigenous population estimates/projections from total estimated resident population and should be used with care, as these data include population units for which Indigenous status were not stated.

Table 6. Perinatal mortality rates, 2003-2005[24]

State/Territory	Indigenous	Non-Indigenous	Rate Difference
NSW	7.5	7.2	0.3
Qld	10.6	8.4	2.2
WA	11.7	7.6	4.1
SA	11.8	8.1	3.7
NT	21.2	9.2	12.0

The rates in Table 6 show that the perinatal mortality rates are higher for Indigenous babies in every state/territory with adequate data except for NSW where the rates *appear* to be nearly identical. The highest perinatal mortality rates for both Indigenous and non-Indigenous babies *appear* to be in the Northern Territory, which also has the largest absolute difference in rates. However, the completeness of Indigenous identification is highest in the Northern Territory and is lower in NSW and Queensland. Therefore, we cannot definitively state that these rate differences are accurate reflections of underlying differences in health status without further analysis of levels of under-identification and statistical adjustments.

Because there is no linked birth-death file in Australia, the data on infant mortality in Table 7 come from separate sources, each with their own levels of under-reporting. While Indigenous infant deaths and births are both underestimated, Indigenous identification in birth data is generally higher than in death data, so the Indigenous infant mortality rate is likely to be an underestimate (AIHW 2007). Thus, we see the same patterns in the rate differences as in Table 6, and again are unable to dissociate differences in health status from differences in identification.

Table 7: Infant mortality rates, 2005-2007[25]

State/Territory	Indigenous	Non-Indigenous	Rate Difference
NSW	8.9	4.5	4.4
Qld	9.1	4.8	4.3
WA	10.2	3.4	6.8
SA	8.9	4.0	4.9
NT	15.7	4.2	11.5

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[24] Source: Overcoming Indigenous Disadvantage Key Indicators 2009 report, web-based detailed appendix tables, based on ABS data calculations. Data tables at www.pc.gov.au/gsp/reports/indigenous/keyindicators2009. Victoria, Tasmania and the ACT are excluded due to small numbers of Indigenous deaths. Deaths for whom Indigenous origin was not stated have not been prorated between Indigenous and non-Indigenous deaths. As a result, Indigenous and non-Indigenous infant mortality rates may be underestimated. Data on deaths of Aboriginal and Torres Strait Islander Australians are affected by differing levels of coverage of deaths identified as Indigenous across states and territories. Care should be exercised in analysing these data, particularly in making comparisons across states and territories and between the Indigenous and non-Indigenous data. Contribution of Indigenous deaths to total deaths is much larger in the NT than in other states.

[25] Same as previous.

There have been significant declines in Indigenous infant mortality in NSW, WA, Qld & NT between 1997-99 and 2005-2007. A reduction in deaths from SIDS over this period seems to be the main driver of this decline (AIHW 2008b).

The data presented in tables 5-7 highlight the following issues:

- Because of small numbers, data is combined across years. However to monitor the targets, an annual rate and rate of change need to be reported.
- Reporting on the targets need to be done for each jurisdiction separately, as combining data from jurisdiction average out the changes in each
- Comparisons of jurisdiction data when measuring targets can be misleading because of the variable level of completeness of identification in these jurisdictions. The application of adjustments factors when robust ones become available will assist in these comparisons.
- The COAG focus to "Close the Gap" on Indigenous disadvantage, have made Indigenous issues highly prominent in Australia. This is likely to impact on identification and this issue need to be considered in the analyses and reporting against the targets through sensitivity analyses.
- Changes in the non-Indigenous population over the same period set for achieving the Indigenous targets will need to be considered in the analyses and reporting against these targets and readjustment made as required.

The challenge for policy makers is how to use the current data effectively to check that they will be on track to reach the target. One strategy that is used is to provide guidance in measuring progress against the targets is to use the best data available for the period of 1998-2007 and then to model trajectories towards meeting the targets under different scenarios (for example, past trends to continue at the same rate, or accelerate as a result of increased resources). Given that there is a great deal of yearly fluctuation in perinatal, infant, and child mortality rates, these trajectories, along with upper and lower bounds, provide a way for the states/territories and the Commonwealth to check their progress toward meeting the goal of lowering the gap in child mortality rates by 2018. As new (and better data) become available, the baseline data will then be readjusted and will become more precise.

Conclusion: Improving Indigenous health monitoring

This paper has demonstrated that current data on Indigenous health are not adequate for measuring the policy goal of reducing the gap in child mortality within ten years, nor are they adequate for analysing the factors which affect infant and child mortality.[26] COAG has recognised the importance of improving the collection of data, and in July 2009 provided around $46 million to "Close the Data Gap" in order to facilitate the process of providing data which can (as much as possible) measure the important policy goal of improving the health outcomes of Indigenous Australians (COAG 2009).

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[26] Although it was not discussed explicitly, because the factors underlying life expectancy are even more complex methodologically than those underlying child mortality, the data are also not of high enough quality to adequately measure the goal of reducing the gap in life expectancy either.

One of the major activities as a result of this funding is to improve census counts and estimates of the Indigenous population including better life expectancy estimates. In addition, a number of other data activities to close the data gaps are described below:

- **Perinatal data:** Improving the National Perinatal Data Collection (NPDC) to better capture maternal and child health outcomes. An enhanced Perinatal National Minimum Data Set is required to collect nationally consistent information on tobacco, alcohol and illicit drug use during pregnancy, antenatal care, and to include information on the Indigenous status of the baby rather than assigning them the status of the mother.
- **Primary care:** Currently Indigenous Australians access a range of primary health care services. This includes Indigenous specific primary health care services, mainstream general practitioners, hospital outpatients and emergency clinics. There is no universally comparable administrative information collected on Indigenous-specific primary health care services. Indigenous-specific primary health care services are funded by the Australian Government, State and Territory Governments, or both. There is a need to improve data systems for all Indigenous-specific primary care services. This will assist in optimising best practice care in these services and will provide a basis for reporting on results and outcomes achieved, particularly in critical areas such as child and maternal health and chronic disease prevention and care. As part of the COAG funding a core national set of primary health care performance indicators will be developed for Indigenous specific primary health care services.
- **Pathology data:** Pathology forms can be an important source of data on cancer (including pap smear screening), communicable diseases, and other conditions and diseases reliant on pathology tests for diagnoses as is the case for chronic diseases. Currently pathology forms do not include Indigenous identifier with the exception of one or two jurisdictions. As a result an important source of data for monitoring Indigenous health status is not available. While for many data sources that rely on pathology the Indigenous status can be obtained from other sources, this is not possible for cervical screening. Unlike breast cancer screening, there are no dedicated screening and assessment services for cervical cancer in Australia. Screening is provided as part of mainstream health services, usually by general practitioners, women health clinics and other community health clinics. Data for cervical screening come only from pathology laboratories to the Cervical Screening Register. Developing a business case for including Indigenous status on pathology forms has been funded through COAG.
- **Assessment of under-identification:** In many administrative data sets, Indigenous Australians are under-identified and this often varies by state and territory and over time. This has hindered and continues to hinder the comparability of these data across jurisdictions. Data quality studies across key data sets are required to assess under identification in key data sets using a number of different methods including audits and data linkage work.. Once adjustment factors for key data sets have been developed, the baselines of the relevant data sets will need to be re-adjusted. This is highly critical because using the current data without adjustment may understate the gap between Indigenous and non-Indigenous Australians in these areas. As part of the COAG funding, work will be undertaken to produce a report on data quality studies used to assess the level of under identification for the different data sets before the work on assessing the level of under identification begins.

- **Data linkage:** Data linkage can be used to assess the level of under-identification of Indigenous status in particular data sets and evaluate the consistency of Indigenous status recording across data sets and over time. At present there are no national standards for data linkage in Australia, particularly in relation to data linkage work to improve Indigenous identification. A nationally co-ordinated approach to data linkage is required to ensure that there is consistency in the methodologies and clerical rules used in data linkage work across jurisdictions and agencies. Standard approaches and procedures for adjusting Indigenous status are also required to ensure data is being adjusted on a consistent basis across data sets. To help ensure the benefits of data linkage are achieved nationally, information on data linkage projects that are being undertaken across Australia should be shared and made available nationally. As part of COAG funding a number of data linkage projects have been funded to assess the level of under identification of Indigenous status in mortality data. This work will assist in regular monitoring of life expectancy and mortality estimates on annual basis.
- **Best Practice Guidelines:** AIHW has developed a draft set of Best Practice Guidelines to improve the collection of information on Aboriginal or Torres Strait Islander people in key national health data sets. These guidelines will be made available to data collectors, data managers and data custodians as a guide for best practices in data collection and management. These guidelines will assist in improving the quality of Indigenous identification in key data sets as well as improve the quality of data linkage activities described earlier. In addition, a communication strategy will be developed in the form of products such as summary brochures, pamphlets, posters to promote and disseminate the guidelines. The aim of the communication strategy is to assist with the implementation of the guidelines and to encourage their use by those who collect, manage and validate data.

Data linkage can be used to create multi-level data sets that would support better analyses of the factors that lead to poor Indigenous health and would be useful for evaluating the impact of health-related interventions with as specific focus on local area analyses. For example, the Perinatal Data Collection could be linked with deaths data to create a linked birth-death file. The individual level data could then be geo-coded to the appropriate community level, where contextual variables could then be attached to the individual-level data, and robust statistical multilevel modelling tools could be used to simultaneously examine the impact of contextual and individual factors. It would also allow for the ability to isolate the impact of key determinants (such as smoking or prenatal care) while controlling for other factors. The data could also be used to create area- or jurisdiction-level probabilities of survival to age one, which may provide a more useful and stable measure of infant mortality than the aggregate infant mortality rate. Longitudinally, data from other sources (such as child health checks, hospitalisations, immunisations, etc...) could be added to get a better picture of the factors affecting child health.

Together, all of these activities will ensure that the data relating to the health and welfare of Australia's Indigenous population are robust and meaningful, and that they can be used to support policies designed to reduce the significant disparities in the health of Indigenous Australians.

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